

## **Factors influencing advance directives among psychiatric inpatients in India**

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# **TITLE – FACTORS INFLUENCING ADVANCE DIRECTIVES AMONG PSYCHIATRIC INPATIENTS IN INDIA**

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**FACTORS INFLUENCING ADVANCE DIRECTIVES AMONG PSYCHIATRIC  
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## **ABSTRACT**

### **Objectives**

Advance directives are documents stating treatment preferences in case of future lack of decision making capacity. In India, as in many other countries, legislators advocate Psychiatric Advance Directives (PADs), while evidence on its use is limited. This study examined factors influencing PADs by gathering inpatients perspectives on PADs at discharge and investigating patient characteristics associated with the expression of treatment wishes in PADs.

### **Methods**

We conducted a hospital based descriptive study in Bangalore. 200 patients were included. The Mini International Neuropsychiatric Interview, CGI-S and CGI-I (Clinical Global Impression scales), the Insight Scale-2, and an Illness insight assessment were completed within 3 days of admission. We used the Bangalore Advance Directive Interview (BADI) to assess attitudes towards PADs. 182 subjects were reassessed within 3 days of discharge, along with an interview on their perspectives on PADs.

### **Results**

67% welcomed the need for PADs in India. 95.6% made their own PADs. 80% followed their doctors' advice in their PAD. Subjects lacking insight or remaining symptomatic at discharge opted significantly more often against ECT, antipsychotics, and inpatient care. Linear regression showed that low socio-economic status, unwillingness to stay in hospital, and having received ECT before were inversely associated with the expression of treatment wishes in PADs.

## **Conclusions**

This study's findings are relevant for India and Western countries alike when generating legislation including patients' perspectives. A majority of patients favoured PADs. Absent insight, severe psychopathology and incomplete recovery may negatively influence the way PAD are completed. Therefore, clinicians must assess patient's capacity to formulate PADs carefully, as capacity may significantly influence patients' views. The timing of when to formulate one's PAD within the illness process may be essential.

## 1. Introduction

In India, the concept of Psychiatric Advance Directives (PADs) is outlined in The Mental Health Care Act -2017. This Act came into force on the 7<sup>th</sup> April 2017 after the president of India signed the Bill. India is one of many countries in the process of including Advance Directives in health legislation. The main reason for this is political and developed after India ratified the United Nations Convention on Persons with Disabilities (UNCRPD) in October 2007, rather than based on evidence supporting the efficacy of Advance Directives (Sarin et al, 2012). The current Act was introduced to overcome the inadequacies of the existing Mental Health Act, 1987. It was necessary to align and harmonize the existing Indian laws with the principles of human rights as defined in the United Nations Convention on Persons with Disabilities (UNCRPD). Advance Directives are a key element in the new mental health legislation in order to achieve this harmonization..

Advance Directives are documents made by patients with decision-making capacity stating treatment preferences in case of future lack of capacity (Hoge, 1994; Srebnik & La Fond, 1999; Lepping, 2003). The concept of Advance Directives originated from the “Right to die movement” in the United States nearly half a century ago. Especially with regards to end of life decisions Advance Directives are integrated into health care in many countries. Initially, health care decisions were determined by professionals following principles of beneficence (Oddi, 1994). With the Psychiatric Self Determination Act (PDSA) passed in 1994, the United States formulated the first legislation that included patients’ rights to make decisions on aspects of their own treatment. Since then many countries around the world have developed legislation that allows patients with capacity to make advance statements about their treatment wishes in case of future incapacity. This includes decisions on psychiatric treatment, although mental health legislation often restricts such choices (Carson & Lepping, 2009).

The former Indian Mental Health Act of 1987 contained no provisions for a Psychiatric

Advance Directive (PADs), neither by the patient nor by a Nominated Representative. In contrast, the Mental Health Care Act, 2017, outlines in Section 5 that an Advance Directive in Psychiatry must comprise the following aspects:

1. Treatment modalities desired (treatments wanted by patient)
2. Treatment modalities not desired (treatments refused by patient)
3. Nomination of a surrogate decision maker in case of patient's incapacity

Such an Advance Directive needs to be written in the presence of two witnesses and a certificate of competence must be obtained from a General Practitioner or a Registered Medical Practitioner. According to The Mental Health Care Act-2017, capacity will be assessed as follows: A person has capacity if the person has the ability to:

- a) understand the relevant information to take decisions regarding treatment or admission or personal assistance; or
- b) understand the consequences of making a decision or lack of decision on the treatment or admission or personal assistance; or
- c) communicate the decision by verbal or non-verbal means of communication.

No formal capacity assessment tool is required. The PAD needs to be submitted to the District Mental Health Review Committee (MHRC). However, registration is not absolutely required to make the PAD legally binding. The draft allows the provision of amending, cancelling or revoking the PAD at any point in time. A blanket refusal of any kind of treatments is considered invalid, unless approved by the district panel of the MHRC. The PAD therefore requires a clear formulation of the patient's preferences and refusals. An appeal is to be made before the MHRC in cases of requests to overrule the PADs. PADs written within 72 hours of receiving emergency treatment will be considered invalid (MHCA-2017, Sarin, Murthy, & Chatterjee, 2012).



There are very limited existing studies on PADs from India. A study from the SCARF foundation shows psychotic patients with a long-term illness were able to make valid PADs irrespective of their education and locality of stay (Kumar et al., 2013). In another 2013 study, patients decided about treatment (passive, active, and collaborative) depending on the situation and decision at hand, and had high levels of self-efficacy (Shields et al., 2013). Another recent study from south India by Pathare and his group investigated service users and their families' opinions about the new legislation. In that study, most users agreed to formulate a PAD and were comfortable in appointing a nominated representative (Pathare et al, 2015). PADs are, however, not yet common practice. There is limited empirical experience to understand what is necessary to successfully implement advance directives into psychiatric care in India (Sarin, Murthy, & Chatterjee, 2012). Legally, all adults, including those with mental illnesses, are presumed competent to make health care decisions unless proven otherwise. In India, a family commitment is required for admission because of the obligation to take care of family members in hospital. This constellation may well be expected to lead to more patients or family members filling in PADs (Shields et al., 2013).

The inclusion of Advance Directives in the law is burdened by a number of issues, especially in middle and low-income countries such as India. The literacy of patients in mental health care can be limited. Many may not understand the merits of appointments made in Advance Directives. It is often unclear to which extent Advance Directives are really understood by patients or their caregivers. Once back home, they may forget these appointments or it may not be feasible to uphold them due to economic restraints. Experience in using Advance Directives remains scarce as resources to draw up Advance Directives with patients or their next of kin are scarce. In a systematic review that included studies primarily from high income countries, Lepping et al found that across inpatient and outpatient psychiatric populations the weighted average proportion of patients with incapacity was 45% (95%

confidence interval (CI) 39-51%) (Lepping et al, 2015). This indicates that assumptions about patients' capacity to make Advance Directives should be approached with caution and careful assessments of capacity are required before such directives become valid and applicable.

Some authors have criticized placing too much value on capacity at the neglect of beneficence and good outcome (Lepping & Raveesh, 2014), but despite all criticism capacity remains the cornerstone of autonomous decision making in most legislative frameworks around the world. It is important to delineate capacity from competence. Mental capacity is a multidimensional construct with capacity in the centre of an individual's ability to make autonomous decisions (Okai et al., 2007). Competence is a legal term determined by a court. In contrast, capacity is a medical term usually used by mental health professionals who determine a person's capacity to make certain choices (Lepping, 2003).

Another complex issue is the severity of the patient's psychiatric disorder, which may be different when the Advance Directive is drafted compared to when it needs to come into effect. Severe Mental Illness (SMI) is often characterized by alternating periods of capacity and incapacity (Srebnik & La Fond, 1999). Incapacity is a common feature of an acute exacerbation of mental illness with especially high prevalence of incapacity in acute mania and psychosis (Owen et al., 2013). During such exacerbations, patients often refuse treatment, but such refusals do not necessarily reflect the patient's true wishes, nor are they consistent over time (Owen et al., 2009a; 2009b). Therefore, PADs are relevant in mental illness with alternating capacity. PADs thus provide people with SMI the opportunity to convey their treatment preferences when they have capacity (Campbell & Kisely, 2009). Moreover, PADs can empower individuals to make decisions about their treatment and appropriate care, in turn leading to less perceived coercion and improved treatment motivation and adherence (Swanson et al, 2006). PADs allow timely and early interventions and provide the opportunity to help prevent the escalation of the patient's illness in the case of current and future admissions.

Several recent studies (Thornicroft, 2013; De Jong et al, 2016) show that Advance Directives are associated with fewer compulsory admissions and less coercion.

In this context, Zelle (Zelle et al., 2015) recently stated that PADs are thought to “embody a recovery-oriented philosophy” by encouraging [patients] to preselect their treatments for times of future crises. How to embed PADs in treatment is essential. A large spectrum of advance statements emerged in a number of high-income countries like PADs, Facilitated Advance Directives, joint crisis plans, crisis cards, treatment plans, wellness recovery action plans, Self-binding Directives, and Advance Refusals (Gergel & Owen, 2015; Henderson et al, Swanson, Szmukler, Thornicroft, & Zinkler, 2008; Lepping & Raveesh, 2014; Sarin, Murthy, & Chatterjee, 2012). These vary in their goals, the level of involvement of the care provider, the role of the third party, the determination of competency or capacity, the nature of the advance agreement, and the degree to which they are legally binding (Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008). It is important that Advance Directives are legally binding so that patients can be confident that their wishes are carried out. This also allows doctors to keep to the patient’s Advance wishes without fear of retribution. Furthermore, as an added benefit it may reduce the need for coercive measures (Verlinde et al, 2016).

Despite a vast body of literature advocating the use of PADs, evidence for their efficacy remains scarce, in terms of outcome expressed as improved mental health or reduced service use, fewer compulsory admissions or coercive measures (Campbell & Kisely, 2009; Zelle et al., 2015). In one non-randomised study, the intervention group (PADs) showed a significant improvement in working alliance and treatment satisfaction at one-month follow-up (Swanson et al., 2006). A number of studies failed to show differences in involuntary admission rates, numbers of readmissions, days spent in hospital, length of involuntary or subsequent voluntary admissions or satisfaction with psychiatric services at follow up (Papageorgiou, King, Janmohamed, Davidson, & Dawson, 2002; Papageorgiou, Janmohamed, King, Davidson, &

Dawson, 2009; Henderson et al., 2004). A more recent randomized controlled trial confirmed the relative ineffectiveness of PADs on psychiatric outcome parameters such as involuntary hospital admission, length of stay, perceived coercion and engagement with services. The study argued that despite improved patient satisfaction, engagement as well as patient rated therapeutic relationships implementation in daily practice remained difficult due to a large variation in engagement of clinicians. Patients in the intervention group (with PAD) were, however, less likely to be violent than the control group (Henderson et al., 2015), implying some clinical effect.

Consequently, authors of a recent Cochrane meta-analysis advised against PADs because of a lack of clear scientific evidence for their clinical benefits. (Campbell & Kisely, 2009). Patients' level of competence and their type of disorder may be related to their willingness to participate in advance directives (Flood et al., 2006). Many patients may refuse participation in studies for a number of reasons, which has been a consistent problem over time (Brown, 2003, Zelle, 2015). Moreover, family participation seems to be a key issue in PADs participation rates (Muthappan, Forster, & Wendler, 2005). In high-income countries, the few existing studies suggest varying participation rates in Advance Directives. A large early New York state sample showed a participation rate of only 11% (Swanson et al., 2006). Rates between 4-13% were reported in more recent large samples in five American cities, and rates of 29% in the English NICE Guidelines evaluation (Jankovic, Richards, & Priebe, 2010; Mears et al., 2008). Rates of up to 62% were reported in a small Canadian sample (Bravo et al., 2011), and 86% in a small Australian sample (Wauchope, O'Kearney, Bone, & Urbanc, 2011). The different methodologies in data acquisition, however, make any comparisons unreliable.

With respect to patients' characteristics several recent studies examined whether specific illnesses have an influence on patients' capacity and thus their ability to make valid Advance decisions. Results were reported for bipolar disorder (Gergel & Owen, 2015),

personality disorders (Borschmann et al., 2014), cognitive disorders in the elderly (Garand, Dew, Lingler, & DeKosky, 2011), and psychotic disorders (Ruchelewska et al, 2014, Kemp, Zelle, & Bonnie, 2015). The authors hypothesised that the common denominator of most of these disorders is a fluctuating mental capacity, leading to variable degrees of impaired capacity (Kemp, Zelle, & Bonnie, 2015). It may be expected that these disorders are associated with a higher use of Psychiatric Advance Directives, because they increase the risk of loss of capacity. Consequently, these disorders may also be expected to be associated with differences in how Psychiatric Advance Directives are written.

In total, only four randomized controlled trials could be traced in an extensive review covering 78 publications from 1972 up to 2016 onwards, in addition to a number of cohort studies. Two recent studies advocate that there may be some evidence for following a specific approach providing different directives in different patient groups (Borschman et al 2014; Ruchelewska et al, 2014; Gergel & Owens 2015). In implementing Psychiatric Advance Directives a number of these studies discuss the importance of a sound implementation of care planning (Bisson et al 2009). The evidence based studies all share the notion that Advance Directives need to be carried out in a systematic way, covering the same phases in the treatment process. This process starts with formulating appointments, then appointing a nominated representative, and finally designing a follow up after discharge.

A number of American and European studies suggest that patients' willingness to write Advance Directives depends on the health care workers' ability to match their frame of reference to those of the patient (Amering, Stastny, & Hopper, 2005; Bee, Price, Baker, & Lovell, 2015). Such a match could increase participation and treatment success in patients with serious mental illness significantly when embedded in a structured approach (Swanson et al., 2006; Elbogen et al., 2007; Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). In short, many contextual and patient related items influence the rate of participation with Advance

Directives. The mental capacity of the patient, a willingness to accept advice, and adequate timing of discussing the directive with the patient seem to be the most important factors, alongside the country's culture with respect to the patient's willingness to consider health professionals' advice.

The Mental Health Care Act-2017 generated a great deal of debate, criticism and controversy related to issues such as Advance Directives, Nominated Representative, mental capacity assessments, unmodified ECT, decriminalising suicide, prohibition of ECT in minors, Central and State Mental Health Authority, and the establishment of the MHRC and mental health review board, which may be perceived as a quasi-judicial body (Fudosi and Ahmad, 2016). Some authors have criticised the law as overambitious within the context of the current Indian mental health workforce, infrastructure and resources [Narayan & Shekhar, 2015]. However, there appears to be a tendency for courts to interpret patient rights more rigorously even when there is a potential lack of resources to implement the decision. A good example of this is a recent court decisions in England and Wales where lack of time or resources were deemed to be irrelevant for the interpretation of the law on consent (Sokol, 2015).

Because admission at a psychiatric ward requires family or next of kin to care for the patient, family and friends are intimately involved in the patients' care in India. They have an indispensable role not only in managing the patient's illness but also in recovery and restoring functioning and quality of life. Decision-making is often collective, in collaboration with medical staff (Lepping et al, 2016). Irrespective of the lack of evidence for the benefits of PADs, India is about to implement them into psychiatric care. Recently, Pathare investigated service users and their families' opinions about the new legislation. In that study, most users agreed to formulate a PAD and were comfortable in appointing a nominated representative (Pathare et al, 2015). Contrary to studies in high-income countries, patients almost all adhered to treatment suggestions made by doctors. While medication and treatment were well adhered

to, ECT was refused by more than half of participating patients. No patient used the opportunity to refuse treatment outright.

Indian mental health care is divided into government run hospitals to which everybody has access for a minimal fee or free medical services, and private health care facilities, which are expensive and unaffordable to a significant part of the population. Besides the fact that family is required to provide care during admission in India, mental health care is less accessible than in most high and comparable middle income countries. 2014 WHO data show that compared to most high income countries bed and clinician availability is significantly lower in India. For example, in the United States, there are 35.03 mental health beds per 100,000 population; in the UK 34.08, in France 89.65, in China 16.76, and in Thailand 6.93. However, in India there are only 2.05 beds per 100,000 populations, a third of which are in general hospitals. According to 2014 data from the WHO, India has 0.30 psychiatrists and 0.12 psychiatric nurses per 100,000 populations. This compares unfavourably to 12.40 and 4.25 in the United States, 14.63 and 67.35 in the UK, 14.12 and 90.86 in France, or 0.87 and 4.46 in Thailand (no data available for China). This context needs to be taken into account as we consider the findings of our study.

Whether India is ready to prove PADs feasible and practical is still an unanswered question, as there is a lack of knowledge of PADs among patients and service providers. In the daily practice of the family-oriented culture, there are many difficulties in communicating PADs to patients and empowering them to make decisions about their treatment. These considerations produce a pressing need for a study looking at patients', carers' and service providers' perspectives on PADs. This study takes a next step by identifying patients' views on PADs and relating these to their clinical as well as their socio- demographic characteristics with a substantial number of patients. It produces the first empirical evidence on PAD within

India's mental health care provision. It explores whether PADs are feasible in the Indian context and culture, to which extent, and in which patients.

## **2. Aims and objectives**

The aim of the current study was to investigate psychiatric inpatients perspectives on advance directives at the time of discharge, and to understand which patients may benefit most from the advance directives. The main questions were:

1. Are patients willing to write Psychiatric Advance Directives (PADs)?
2. Which treatment preferences do patients mention in their PADs?
3. Which patient characteristics determine the patients' PADs preferences?

## **3. Methods and Materials**

### **3.1 Design**

The study is a hospital based descriptive cohort study, conducted at the Department of Psychiatry, National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore-29, India. The study was conducted between June 2013 and September 2014. A total of 467 consecutive patients were chosen by computer generated random number sampling and screened in accordance with the study protocol. Patients affected by learning disability, organic brain syndromes, delirium, dementia, developmental disorders and antisocial personality disorders were excluded from the study. The exclusion criteria were chosen because some cognitive ability allowing reflection about one's own future treatment and preference was required, as we were interested in patients' willingness to write Advance Directives. These choices were made based on experience gathered in the pilot preceding the main study. After



comprehensively describing the study to the subjects and their relatives, written consent was obtained from either patient, family members or other relevant attendants in accordance with the ethical approval obtained for the study. This is important, as some of the patients may have lacked capacity to consent at the time of their first assessment. Two hundred fulfilled the inclusion criteria and consented to assessment at baseline (Figure 1). One hundred and eighty two of these were interviewed within 3 days of discharge. The remaining eighteen patients either absconded or had discharged themselves against medical advice. The response was 77% to PADs with a net response of 91% and a low attrition rate of 9%.

Figure – 1 about here

### **3.2 Assessments**

Interviews were done by the first author on an admission ward. All patients were interviewed within 3 days of admission and re-interviewed within 3 days of discharge. A questionnaire containing predetermined questions and answer categories covered socio-demographic details, information on the number of previous admissions, the illness, and inpatient stay duration. Patients, family members, and psychiatrists were asked to complete the questionnaire. In this way information from various (electronic) sources were compared. The information obtained from interviews was supplemented by information from the medical charts. Psychiatric diagnosis was made according to ICD-10 criteria by using the Mini International Neuropsychiatric Interview (MINI 5.0, Sheehan et al., 1998) at admission. The Clinical Global Impression scale (CGI) was used to assess the severity of illness on admission and to estimate the global improvement of illness (Guy, 1976) at discharge. Insight was evaluated with the insight Scale-1, expressing insight as full, partial or no insight, based on

awareness, attribution and acceptance of problems and willingness to take treatment (Sadock & Sadock, 2007a). With the Insight Scale-2, insight was rated on a 5-point scale from complete denial of illness through full emotional insight and acceptance of problems and willingness to take treatment (Saddock & Saddock, 2007b), also at admission and discharge. We used Insight at Discharge, CGI-severity and Global improvement at admission and discharge for our analysis.

### **3.3 Bangalore Advance Directive Interview.**

To assess patients and caregivers wishes with respect to Advance Directives, the Bangalore Advance Directive Interview was developed. This is a semi-structured interview held by a trained researcher constructed along general questions with predetermined answer categories. If the response on an item was ambiguous, both a negative and positive answers were recorded. We validated the interview in two pilot studies. First, we interviewed fifteen patients to assess patient's perception, their experience in the provision of advance directives and future treatment preferences. The findings of these interviews were then presented and modified in collaboration with the 30 Consultant psychiatrists in the department to produce the finalised Bangalore Advance Directive Interview (BADI) as presented in the appendix of this paper. In this study, we applied the BADI at the second assessment just before discharge. Reliability and construct validity of the instrument were tested.

The BADI was developed for the research study purpose. Those patients who made their PADs through BADI are informed in advance that it is just a research exercise for the study and it will not be valid in clinical practice. All patients who are included in the study were invited to write the PADs without being pressurised, coerced or persuaded by a researcher to make a PAD for research purposes.

### **3.4 Statistical analysis.**

Clinical and socio-demographic characteristics of the sample were analysed by descriptive statistics. In continuous variables such as age and CGI at admission or discharge T-test and analysis of variance (ANOVA) was because of the explorative nature of the study, straight counts of all major items of the study were calculated along with analyses into relations between variables. Chi-square was used to assess differences on Bangalore Advance Directive Interview (BADI) items between patients with or without insight, improved versus not improved, and mentally ill versus not ill at discharge. The scale reliability data for the BADI was calculated (Cronbach, 1951). In addition, after investigating scale distribution, a linear regression analysis (David & Freedman, 2009) on the sum score of the BADI was performed to relate background characteristics to wishes expressed in the Advance Directives. Patient characteristics, diagnosis, clinical global impression and insight may be seen as independent variables, the treatment preferences as expressed in advanced directives measured by the BADI as dependent variables. Statistical analyses were performed using the level of statistical significance set at  $P < 0.05$ .

## **4. Results**

At discharge, 182 patients were available for the second assessment. Table 1 presents socio-demographic characteristics and clinical characteristics of the study sample.

Table -I here

Of the 182 participating patients, 67% (n= 122) welcomed the need for PADs in India. 24% (n=43) were ambivalent, and 9% (n=17) rejected the need for PADs in India. It was interesting that almost all patients (98%, n=178) wished to receive treatment for a future mental illness. Out of 182 patients, 174 (96%) patients formulated their own PADs during the study period. Whereas most variables reflect the demographic composition of the catchment area, education levels of the responders in the study are higher than may be expected, making some selection bias of included patients possible.

Table 2 presents details about patient PADs at discharge and the role of insight in making PADs. Out of 174 patients who filled in the PADs, 94 % (n=162) chose a nominated representative. Most patients chose their parents (44%, n=71) or spouse (33%, n=54). A minority of patients chose their son (7%, n=12), brother (7%, n=11), daughter (4%, n=6), sister (0.5%, n=1), another relative (3%, n=5), or friend (0.5%, n=1). Patients expressed their wish to be treated as advised by their doctor or psychiatrist in 80% (n=140) of cases, by the Mental Health Establishment or General Hospital Psychiatric Unit in 65% (n=113) of cases. They opted for outpatient care in 57% (n=100), inpatient Care in 43% (n=74), psychotherapy in 18% (n=31), and non-allopathic treatment in 0.5% (n=1) of cases. Patients expressed that they did not wish to be treated with ECT in 58% (N=101) of cases, not by Faith Healers in 59% (n=103), not with psychosurgery in 57% (n=100), not with injections in 14% (n=24), and generally not with any medicine in 2% (n=4) of cases. Figures are rounded to the next full number.

Furthermore, we present the relationship between PADs with CGI improvement scores (CGI-I) at discharge and the severity of illness as measured by CGI-S scores between admission and discharge (Table 2). The analysis showed that patients with full insight at

discharge, complete improvement of their illness and no symptoms at discharge as measured by the CGI-S, agreed significantly more often to following psychiatric advice in an inpatient setting. Patients with absent insight, ongoing symptoms at discharge, or showing less clinical improvement in general rejected ECT, injections, medication and inpatient care.

*Table 2 here*

Table 3 presents the findings of the linear regression analysis, using the scale sum of the Bangalore Advance Directive Interview as outcome. Scale analysis showed a reasonable reliability for the positive wishes (positive treatment choices) of Advance Directives (Cronbach's  $\alpha=0.58$ ), and a good reliability (Cronbach's  $\alpha=0.69$ ) for the negative wishes (treatment refusals) of Advance Directives. One may thus postulate that it is easier to state what you do not want than what you do. A first analysis showed a normal distribution and final scale reliability including all items was reasonable to good (Cronbach's  $\alpha=0.65$ ), allowing the use of the scale as an outcome.

Using this scale as a linear outcome measure, a number of diagnoses, such as schizophrenia, bipolar affective disorder, depression and drug or alcohol abuse proved to be related to positively expressed treatment wishes in the Advance Directives. In contrast, low socio-economic status, patient involuntary status and having experienced ECT showed an inverse relationship with positively expressed treatment wishes of Advance Directives (Table 3).

*Table 3 here*

## 5. Discussion

The findings of this study showed that many patients in India agree with Advance Directives and indeed formulated one. Positive expressed wishes in the Advance Directives showed a positive association with several severe mental illnesses such as Bipolar Disorder and Schizophrenia, confirming findings from previous randomized controlled trials with cohorts from high income countries. The findings also supported the findings of a qualitative study into patient's preferences by Pathare et al (2014). In line with the latter Indian study, compliance and treatment adherence were far better in our sample than in many high income countries, and ECT was favoured less.

Most patients opted for outpatient care above inpatient care in case of future incapacity. Most opted for treatment as advised by their psychiatrists. This shows patients' trust in doctors in India but may also simply reflect a higher degree of medical paternalism that is accepted by patients. A majority rejected treatment from Faith Healers, non-allopathic treatment or neurosurgery. This may show increased awareness and knowledge about mental illness among patients. It may also reflect a changing trend in seeking mental health care from mental health professionals rather than from non-professional sources that are more traditional. Of course, our sample was recruited in a university hospital and may simply reflect the preferences of those who attend such a setting. Full insight at discharge and complete improvement of symptoms were associated with compliance with psychiatric advice and treatment in inpatient settings. Those with absent insight or ongoing symptoms at discharge tended to refuse ECT, other treatment and inpatient care. It is beyond the paper's remit to understand whether these refusals are views based on experience, attitude or whether they would change once insight is regained. In real life of course, these patients would not have been likely to have sufficient capacity to make valid PADs. Lack of capacity is influenced by many factors, but poor insight

into their illness and incomplete recovery are common reasons well described in the literature. PADs made during such periods do not necessarily reflect the patient's true wishes, nor are they consistent over time (Owen et al., 2009a; 2009b). However, such refusals may also express a real difference in opinion between psychiatrist and patient, as patients may have experienced side effects or no treatment effect, resulting in disagreements about therapeutic options.

We conclude that the majority of patients may have capacity to make advance directive at the time of discharge, so encouraging the patient to write a PAD may help improve treatment opportunities in case of readmission in the future. Our findings underline the importance of embedding PADs in the treatment process, in line with the suggestions of Thornicroft (2013) and Henderson (2016). Whilst there is a legal requirement to assume capacity until proven otherwise, doctors need to be mindful of the high probability that their patients may have limited decision-making capacity. They need to regularly assess the patient's ability to understand treatment options. Especially in the Indian context family opinions need to be taken into account. Unlike in European and to some extent American studies, Indian patients in our study mostly engaged family in their decision-making. Almost all patients asked family members to be their nominated representatives. In their response, patients were more consistent in what they did *not* want, as opposed to what they *did* want. A consistent choice in Advance Directives was related to the diagnoses schizophrenia, bipolar affective disorder, depression and drug or alcohol abuse. Being of a low social economic background, showing insufficient recovery, having experienced ECT and having been involuntary admitted were associated with less consistent choices in Advance Directives and treatment refusal.

The finding that positive wishes were less reliable than treatment refusal should be considered in future studies. It appears to be relatively easy for the patient to formulate what they did not want as treatment or care for their future mental illness. It is more specific compared to formulating what the patient does want. We hypothesise that this may be for the

following reasons: Those who had adverse experience with specific treatments remember this and find it easy to refuse them in their PADs. Those who want to express positive choices for treatment and care become broader and vague because treatment for each mental illness is specific and individualised treatment will be planned based on severity, affordability, availability under their health insurance scheme, and many more factors. In contrast to European settings, affordability is a very real issue for Indian patients.

Our results were similar to the SCARF Study from south India (Kumar et al., 2013), and the study by Pathare (2015) where most patients wrote a PAD. In our study, the socio-economic status of patients (as reflected in educational level and in the percentage of patients earning above BPL) was higher than in other Indian studies (Kumar et al., 2013; Raveesh, et al., 2015; Danivas et al., 2016).. However, it may also simply reflect the economic prosperity of the South Indian area, as compared to the other regions where comparable studies were performed.

Our study showed that treatment preferences in PADs are not influenced by any individual socio-demographic variables, such as gender, educational level, or social class. Severity of diagnosis showed a clear relation to expression of wishes in PAD in the regression analysis. As such, the group of patients who opted to refuse future treatment was more likely to lack capacity and was more ill on discharge and therefore likely to lack capacity to formulate valid PADs. Studies by GS Owen and his group (Owen et al., 2009; Tiwari & Pandey, 2014), looking into factors influencing a patient's capacity to make treatment decision, support this finding. In their study, patients with psychotic disorders, manic episodes of bipolar affective disorder, and no insight into their illness showed less capacity and were less likely to succeed in formulating PADs (Elbogen et al., 2007; Owen et al., 2013).

The Mental Health Care Act 2017, Section 5, outlines the need for the person formulating a PAD to have capacity to make such a decision. Systematic structured clinical



assessments of mental capacity have been found useful in assessing a person's capacity to formulate a PAD, but are not specifically required by the Mental Health Care Act 2017. Furthermore, clinicians ought to assist and support a person with mental illness in decisions about their care and treatment. In India, most decisions about treatment are collaborative (Lepping et al, 2016) and variably influenced by social and medical paternalism. This was reflected in the finding that almost all patients interviewed opted for treatment and care as advised by treating psychiatrists even when they are asked to write their own choices of care and treatment.

## **6. Strengths and limitations**

To the best of our knowledge, this is the first prospective study in India on patient views of PADs at discharge. Furthermore, this is the first study looking at patients', families, and clinicians' perspective on PADs. However, we focused on the patients' perspective on PADs in this paper. The study included all patients who are admitted either voluntarily or involuntarily. All patients were recruited and interviewed within three days or at time of admission and assessed with face-to-face interview by researchers using a validated scale. The study also has some methodological limitations:

1. The study was limited to inpatients; it did not include outpatients or a community sample.
2. The population was predominantly from the south of India and may not be representative the Indian population as a whole.

The study has a number of strengths. We succeeded in including patients who were severely mentally ill on admission, adding to the clinical validity of the findings. We achieved a high response and low attrition rate. Of the patients satisfying the inclusion criteria, 84%

participated in the study and 77% could be included in follow up. This makes it highly likely that the response rates are representative of patients who may use Advance Directives in the Bangalore Hospital, where the study was conducted. Finally, the BADI showed reasonable to good construction validity parameters, the questionnaire was developed by expert opinion in an academic centre, further adding to the clinical validity of the findings.

## **7. Conclusion**

A majority of patients in this sample in India welcomed PADs. Most patients wanted to be treated psychiatrically again in case of future illness. Absent insight, severe psychopathology and incomplete recovery may influence PADs statements, and therefore great care should be taken to ensure that patients who formulate a PAD have the capacity to do so. In that respect a better family engagement and fine-tuning treatment to the mental state of the patient is a lesson to be learnt from this experience. For policy makers it is important to recognise that patients who lack capacity in any setting are not able to formulate Advance Directives, as any wishes defined whilst lacking capacity do not necessarily reflect the patient's true wishes and are often not consistent over time.

## **Acknowledgments**

**Compliance with ethical standards:** Written consent was obtained for assessments at discharge. The study was performed in accordance with the ethical standards laid down in the Declaration of Helsinki, 1964 (World Medical Association Inc, 2009).

**Conflict of interest:** The authors declared no conflict of interest.

**Ethical approval:** The Institutional Ethical Committee (IEC) of the National Institute of Mental Health And Neurosciences (NIMHANS), Bangalore approved the study; Sl.No:03, Behavioural Sciences/ NIMH/DO/SUB-COMMITTEE/2013, dated 01/06/2013.

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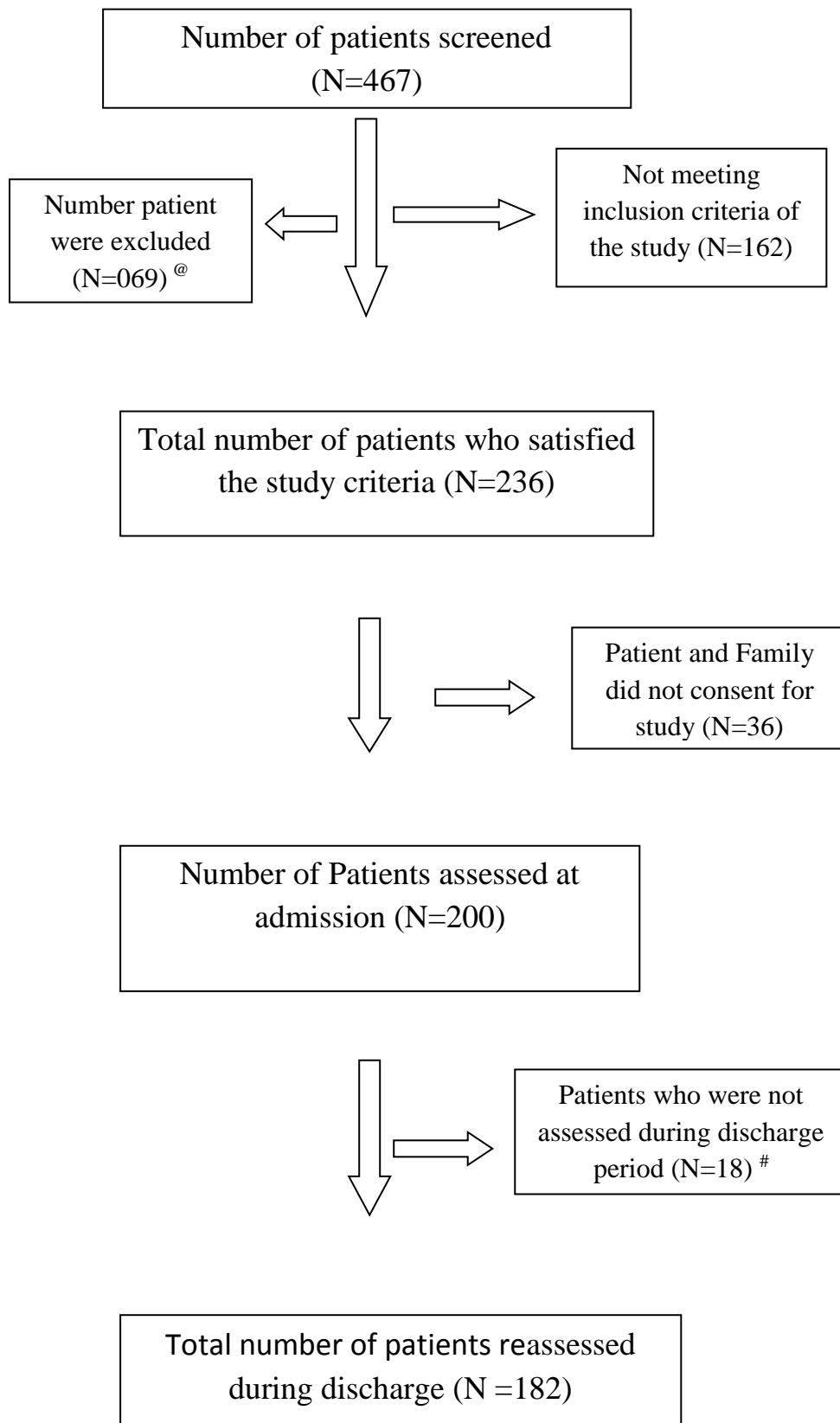
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**Figure -1: Flow Chart**



**Patients who were not assessed during discharge (N=18) #**

- ❖ Nine subjects absconded during admission period.
- ❖ 12 subjects were discharged against medical advice but 7 subjects discharge assessments was done
- ❖ 6 subjects were discharged at request and discharge assessments was done
- ❖ 4 subject were not traceable / not consented for study

**Patients who were excluded [N=69] @**

- ADS in C W S (Delirium /Seizures ) - 18
- Axis -1 diagnosis with Mental retardation - 14
- Axis -1 diagnosis with organic brain syndromes / delirium / dementia - 8
- Patients who do not have family members at the time of admission - 29



**Table – 1: Patient characteristics (N=182)**

Item		Findings
Age in years 18-30		47%
	> 30	53%
Age in years	Mean (SD)	33.9 (11.4)
Education in years	Mean (SD)	9.1 (4.8)
Education	no formal	13%
	<7 <sup>th</sup>	19%
	8 <sup>th</sup> - 12 <sup>th</sup>	48%
	> 12 <sup>th</sup>	20%
Gender	Male	54%
	Female	46%
Employment	Employed	11%
	Unemployed	80%
	Never employed	9%
Religion	Hindu	91%
	Muslim	6%
	Christian	3%
Family Type	Nuclear family	69%
	Extended nuclear family	12%
	Joint family	14%
SES	BPL	69%
	APL	31%
Marital Status	Single	41%
	Married	46%
	Separated	8%
	Widow/er	5%
Language	Kannada	86%
	English	4%
	Hindi	4%
	Other	6%
Location	Rural	57%
	Semi urban	30%
	Urban	30%
Diagnosis	Schizophrenia and psychotic disorders	47%
	Mood disorders ( BPAD + Depression)	44%
	Others	9%
Co morbid	Alcohol Dependence syndrome	15%
	Nicotine Dependence syndrome	28%
	Other Substance Dependence syndrome	4%
Admission type	Involuntary	74%
	Voluntary	26%
Willingness to stay	Unwilling to stay	66%
	Willing to stay	23%
	Ambivalent	10%
Past admission	Present	44%
	Absent	56%
Legal status	Present	5%
	Absent	95%
Insight admission	Present	8%
	Partial	18%
	Absent	74%
Insight discharge	Present	41%
	Partial	54%
	Absent	5%
CGI – S Admission	Mean (SD)	6.09 (0.9)
CGI- S at Discharge	Mean (SD)	1.6 (1)
CGI – GI (Global Improvement) at discharge		1.5 (0.7)
Duration of Inpatient care (days)		21.5 (12.3)
Duration illness in months		72.1 (83.1)
Agreed for Advance directive		174 (95.6)
Opined for Advance directive is necessary in India		122 (67.0)

Table – 2: Relation between Insight at discharge, CGI and locality of Care and Treatment

Variable				Insight at Discharge			CGI - Severity at Discharge			CGI – Global Improvement at Discharge		
				Present n=75	Absent N=107	P	Normal N=110	Mentally ill N=72	P	Very much Improved N=110	Not Improved N=72	P
My wish to get treated [n (%)]	Treatment Setting	Mental Health Establishment or General Hospital Psychiatric Unit	Yes	61%	62%	0.862	61%	63%	0.40	61%	64%	0.403
			No	39%	38%		39%	37%		39%	36%	
		Inpatient Care	Yes	46%	36%	0.111	46%	32%	<b>0.037</b>	48%	29%	<b>0.008</b>
			No	54%	64%		54%	68%		52%	69%	
		Outpatient Care	Yes	52%	57%	0.302	55%	54%	0.493	61(33.5)	39(21.4)	0.49
			No	48%	43%		45%	46%		49(26.9)	33(18.1)	
	Treatment Care	As advised Psychiatrist /	Yes	88%	69%	<b>0.002</b>	84%	65%	<b>0.002</b>	94(51.6)	46(25.3)	<b>0.001</b>
			No	12%	31%		16%	35%		16(8.8)	26(14.3)	
		Psychotherapy	Yes	20%	15%	0.249	61%	64%	0.403	20(11)	11(6)	0.383
			No	80%	75%		39%	36%		96(49.5)	61(33.5)	
		Non allopathic Treatment	Yes	0	1%	0.582	1%	0	0.417	1(0.5)	0(0)	0.604
			No	100%	99%		99%	100%		109(59.9)	72(39.6)	
My wish not to get treated [n (%)]	Treatment Setting	Inpatient Care	Yes	8%	34%	<b>0.000</b>	15%	37%	<b>0.002</b>	16(8.8)	26(14.3)	<b>0.001</b>
			No	92%	66%		85%	63%		94(51.6)	46(25.3)	
	Treatment Care	ECT	Yes	40%	66%	<b>0.000</b>	51%	63%	<b>0.083</b>	56(30.8)	45(24.7)	<b>0.083</b>
			No	60%	33%		49%	37%		54(29.7)	27(14.8)	
		Faith Healer	Yes	58%	55%	0.375	64%	44%	<b>0.006</b>	69(37.9)	34(18.7)	<b>0.028</b>
			No	42%	45%		36%	56%		41(22.5)	38(20.9)	
		Psychosurgery	Yes	53%	56%	0.415	60%	47%	0.062	65(35.7)	35(19.2)	0.108
			No	47%	44%		40%	53%		45(24.7)	37(20.3)	
		Injection	Yes	7%	18%	<b>0.023*</b>	13%	13%	0.493	14(7.7)	10(5.5)	0.49
			No	93%	82%		87%	87%		96(52.7)	62(34.1)	
		Medicine	Yes	0	4%	0.117	0	6%	<b>0.023</b>	0(0)	4(2.2)	<b>0.023</b>
			No	100%	96%		100%	94%		110(60.4)	68(37.4)	

Insight at Discharge

Present = (awareness + attribution + acceptance)

Absent = ( $\pm$  awareness  $\pm$  attribution – acceptance)

[CGI – Severity (CGI –S) = (Normal = 1), (Mentally ill = 2 – 7)]

[CGI – Global Improvement (CGI – GI) = (very much Improved = 1), (Not Improved = 2 – 7)]

**Table -3: Final models of PAD predictors**

Variables	Beta	error	Standard	T	P
(Constant)	7.642	1.376		5.554	.000
Faith healer	.460	.340	.100	1.353	.178
Allopathic healer	.564	.339	.123	1.664	.098
Location back	.419	.241	.131	1.737	.084
Insight	-.631	.350	-.171	-1.803	.073
Religion	-.732	.394	-.134	-1.857	.065
<b>Drugs or alcohol</b>	<b>1.705</b>	<b>.800</b>	<b>.154</b>	<b>2.130</b>	<b>.035</b>
<b>Depression</b>	<b>1.613</b>	<b>.721</b>	<b>.241</b>	<b>2.238</b>	<b>.027</b>
<b>Schizophrenia</b>	<b>1.494</b>	<b>.629</b>	<b>.329</b>	<b>2.375</b>	<b>.019</b>
<b>Bipolar</b>	<b>1.568</b>	<b>.657</b>	<b>.319</b>	<b>2.386</b>	<b>.018</b>
<b>Patient Willingness</b>	<b>-.601</b>	<b>.242</b>	<b>-.223</b>	<b>-2.489</b>	<b>.014</b>
<b>ECT</b>	<b>-1.207</b>	<b>.445</b>	<b>-.195</b>	<b>-2.713</b>	<b>.007</b>
<b>SES</b>	<b>-1.340</b>	<b>.394</b>	<b>-.273</b>	<b>-3.403</b>	<b>.001</b>

## BANGALORE ADVANCE DIRECTIVE INTERVIEW

This interview is constructed with structured questions and predetermined answer sets. The person being interviewed was encouraged to describe the way in which he/she wishes to be taken care for. Patient can chose and discuss regarding different treatment modalities. The Researcher is instructed to hold a neutral position while discussing with patients. Patients could choose any number of options.

BANGALORE ADVANCE DIRECTIVE INTERVIEW						
Sl NO	Treatment care /setting		My wish to get treated /cared for future mental illness	My wish not to get treated/cared for future mental illness		
1	Treatment Setting	Mental Health Establishment				
		General Hospital Psychiatric Unit				
		Inpatient Care				
		Outpatient Care				
	Treatment Care	As advised by Psychiatrist				
		As advised by Doctor				
		Psychotherapy				
		Non allopathic Treatment / Ayush (Ayurveda, Unani , Sidda, etc				
		Faith Healer (temples, mosque, church /native /religious healers)				
		ECT				
		Psychosurgery				
		Injection				
		Medicine				
Others						
2	My wish to be cared for my mental illness by nominated representative					
	By Relative	Spouse		By Care giver	Friends	
		Son			Office/Board	
		Daughter			Other	
		Parents			No one	
		Brother				
		Sister				
		Other relative				
		No one				
	3	I wish, I do not want all future medical treatments or care for mental illness. If yes, please specify reason.				
I feel, I don't feel this treatment is effective						
I feel, I don't have any major problems						
I feel, I can control my illness with meditation and self-control						
I feel, my mental illness is not a illness at all						
I feel, I will never get one more time mental illness.						
Others						